

1 A CONCURRENT RESOLUTION decrying the lack of services and specialized
2 services for medically complex and medically fragile young adults with intellectual and
3 developmental disabilities and directing legislator inclusion on a Cabinet for Health and
4 Family Services 1915(c) Waiver Redesign Working Group and presentations about
5 progress to interim and statutory committees.

6 WHEREAS, individuals who are medically fragile and medically complex
7 encounter many barriers in accessing community-based services, including but not
8 limited to waiting lists for services, lack of service providers who are willing and
9 qualified to provide services, and low reimbursement rates;

10 WHEREAS, at the age of 21, the life expectancy of a medically fragile and
11 medically complex young adult is two to three years because of the substandard care
12 available to this population in our Commonwealth; and

13 WHEREAS, the care available to some individuals younger than 21 who are
14 medically fragile and medically complex and who may require daily skilled nursing
15 intervention such as ventilators, dialysis machines, feeding tubes, or continuous oxygen
16 receive care in pediatric nursing facilities that allows many individuals to thrive prior to
17 age 21; and

18 WHEREAS, because of the lack of community-based services, young people who
19 are medically fragile and medically complex are sometimes placed in traditional nursing
20 facilities designed for end-of-life care;

21 WHEREAS, because of lack of funds at the federal and state levels, the nurse-to-
22 patient ratio drops from about one nurse for every eight patients in a pediatric nursing
23 facility to one nurse for every 24 patients in a traditional nursing facility; and

24 WHEREAS, many medically fragile and medically complex residents are
25 nonverbal, and their needs require anticipation by experienced staff; and

26 WHEREAS, many staff in adult nursing homes are not familiar with the needs of
27 medically fragile and medically complex young adults, including deep suctioning, feeding

1 tubes, and providing medications through feeding tubes; and

2 WHEREAS, young adults have different socialization needs than what is available
3 in adult nursing homes; and

4 WHEREAS, medication timing and frequency changes as these individuals grow
5 older and their care situations change; and

6 WHEREAS, tub bathing for the medically fragile and medically complex often is
7 reduced from once per day in most care settings prior to age 21 to twice per week or
8 fewer in a nursing home; and

9 WHEREAS, access to community age-appropriate activities is greatly reduced for
10 many residents; and

11 WHEREAS, access to educational programs, peer modeling, and socialization is
12 greatly reduced for these citizens after age 21; and

13 WHEREAS, access to critical assistive technology such as standers, gait trainers,
14 and other necessary equipment is compromised; and

15 WHEREAS, private rooms are not available for this population, and they may share
16 rooms with individuals prone to behavior issues, which is particularly concerning for this
17 nonverbal population; and

18 WHEREAS, family members cannot spend the night to visit their family member at
19 many adult nursing facilities; and

20 WHEREAS, there is little availability of bus transportation or other public
21 transportation to many nursing facilities, which further impacts the ability of families to
22 visit residents; and

23 WHEREAS, properly equipped ambulances for transportation of a patient from a
24 nursing facility to a hospital are often not available; and

25 WHEREAS, targeted therapies for this population are extremely limited because
26 many nursing facilities are focused on the aged; and

27 WHEREAS, many of these patients have thrived and survived thanks to medical

1 advances and outstanding care available for medically fragile and medically complex
2 children; and

3 WHEREAS, like other citizens, individuals who are medically fragile and medically
4 complex should have the opportunity to live in the communities of their choice;

5 WHEREAS, the Commonwealth has the opportunity to expand community based
6 services to empower these individuals to continue to thrive;

7 NOW, THEREFORE,

8 *Be it resolved by the House of Representatives of the General Assembly of the*
9 *Commonwealth of Kentucky, the Senate concurring therein:*

10 ➔Section 1. The General Assembly recognizes the important work that the
11 Cabinet for Health and Family Services has begun to redesign the way that services and
12 supports are provided to this vulnerable population through its work with the 1915(c)
13 Waiver Redesign Working Group. The General Assembly directs that a presentation and
14 testimony concerning the progress of this working group be given during the August
15 meeting of the Interim Joint Committee on Health and Welfare and the Medicaid
16 Oversight and Advisory Committee.

17 ➔Section 2. The General Assembly further directs that one Representative
18 selected by the Speaker of the House and one Senator selected by the President of the
19 Senate be added to the 1915(c) Waiver Redesign Working Group to provide legislative
20 input and to address the constituent concerns about medically fragile and medically
21 complex populations in the Medicaid system.

22 ➔Section 3. Sections 1 and 2 of this Act to the contrary notwithstanding, the
23 Legislative Research Commission shall have the authority to alternatively assign the
24 issues identified herein to an interim joint committee or subcommittee thereof and to
25 designate a study completion date.